

Putting the patient at the centre of pathology: an innovative approach to patient education—MyPathologyReport.ca

Anthea Lafreniere,^{1,2} Bibiana Purgina,^{1,2} Jason K Wasserman ^{1,2}

¹Pathology and Laboratory Medicine, Ottawa Hospital, Ottawa, Ontario, Canada

²Department of Pathology and Laboratory Medicine, University of Ottawa, Ottawa, Ontario, Canada

Correspondence to

Dr Jason K Wasserman, Pathology and Laboratory Medicine, Ottawa Hospital, Ottawa, Canada; jwasserman@toh.ca

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ABSTRACT

In many centres, patients now have access to their electronic medical record (EMR) and laboratory results, including pathology reports, are amongst the most frequently accessed pieces of information. The pathology report is an important but highly technical medical document that can be difficult for patient and clinicians alike to interpret. To improve communication and patient safety, pathologists are being called upon to play a more direct role in patient care. Novel approaches have been undertaken by pathologists to address this need, including the addition of patient-friendly summaries at the beginning of pathology reports and the development of patient education tools. MyPathologyReport.ca is a novel website exclusively providing pathology education to patients. It has been designed to help patients understand the language of pathology and to effectively navigate their pathology report. At present, the website includes over 150 diagnostic articles and over 125 pathology dictionary definitions. The diagnostic articles span all body sites and include a variety of malignant, benign and non-neoplastic conditions. Since its creation, this website has been visited over 14 000 times, with cancer-related diagnoses and definitions representing the most commonly accessed articles. This website has been embedded in patient accessible EMRs and shared through partnerships with patients, caregivers and their respective advocacy groups. Our next steps involve longitudinal assessment of MyPathologyReport.ca from non-medical community members, evaluation of patient satisfaction and understanding and further collaboration with hospitals and care-providers to increase patient access to this resource.

The practice of pathology was not built around patients. Known to many as ‘the doctor’s doctor’, pathologists have long been seen as the physician in the background, serving their clinical colleagues. The pathologist’s ‘input’ comes in the form of a tissue sample—the biopsy or surgical resection—typically received from subspecialist physicians for our assessment. Subsequently, the ‘output’ is the pathology report, a technical document designed to provide diagnostic information to a clinician to guide their treatment planning. The pathology report was never intended for patient consumption. Indeed, it can be difficult for even the most experienced oncologist to decipher. And yet, behind the cryptic language and obscure jargon, the pathology report is a document rich in information that is just as meaningful to patients as it is to their clinicians.

Over the past decade, patients have begun to claim their rightful place at the centre of clinical decision-making. In response to the movement calling for a realignment of medicine towards patient-centred care, an increasing number of healthcare providers are providing patients with access to their electronic medical record (EMR).¹ Informal results suggest that laboratory results, including pathology reports, are among the most frequently accessed pieces of information in patient-accessible EMRs.^{2,3} The pathology report is an important source of information regarding diagnosis, treatment and prognosis, but the information can be difficult for patients to understand due to its specialised language.

We, as pathologists, are being called on to become more visible participants in patient care and to help foster an environment that empowers patients. In 2015, the National Academies of Sciences, Engineering, and Medicine released the consensus study entitled ‘Improving Diagnosis in Healthcare’.⁴ This report urged pathologists to become a part of the clinical care team and to collaborate in the patient safety movement, specifically inviting us to communicate with patients and clinicians alike. As patients increasingly access their pathology reports, answering this call will become an essential part of practising pathology.

Can we make pathology reports more accessible to patients while still retaining the essential information our clinical colleagues require? One strategy is to include a patient-friendly summary in each report. One group of pathologists applied this strategy to prostate biopsy reports and found that patients receiving the patient-friendly were better able to recall their Gleason grade and the number of positive cores compared with patients receiving the standard reports.⁵ In a similar study, another group found that patients receiving a patient-friendly bladder cancer pathology report were better able to describe their cancer stage compared with patients receiving the standard reports.⁶ Both of these studies worked with the participating pathologists and patient focus groups to establish the elements to be included in the patient friendly component of the report.

A patient-friendly summary is attractive because it is immediately available to patients and directly applicable to the diagnosis at hand. However, this strategy would be more difficult to apply to less common diagnoses or descriptive reports that do not result in a specific diagnosis. Moreover, it is unclear at this time if there is enough support within the pathology community to develop similar patient-friendly



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summaries in other institutions. In the context of turnaround time pressures and increasing specimen complexity, some pathologists may balk at the idea of having to add additional text to their report before signing it out.

Another strategy involves developing a pathology-focused resource that patients can access to learn more about their diagnosis and the most important elements of their report. Using this approach, we developed MyPathologyReport.ca, a novel website that exclusively provides pathology education to patients. Created in 2017, it is a free online resource designed to help patients understand the language of pathology, to effectively navigate their pathology report and to illustrate the processes of obtaining a pathological diagnosis.

To determine which diagnostic entities would be the most important for patients and their families, the pathology database at The Ottawa Hospital (TOH) was searched to identify the most common diagnoses over a 12-month period. Articles were codeveloped by pathologists and patient groups at TOH and University Health Network (UHN). The articles were written in simple language with explanations provided for unfamiliar words. Through the website, patients are invited to submit new article ideas and to propose changes to existing articles. New articles are distributed to an online group of 'patient advisors' who provide feedback, revise and make suggestions to improve the article prior to the article going online.

Since its launch in December 2017, the website has received 14392 visitors (as 28 January 2020). Of these, 1506 accessed the website directly from a link in the UHN EMR. The website has 163 diagnostic articles and 132 definitions contributed by 25 Canadian pathologists. To ensure quality, a member of the editorial board reviews all articles prior to publication. The diagnostic articles span all body sites and include a variety of malignant, benign and non-neoplastic conditions. The definitions are meant to explain common pathology terms, such as grade, atypia, margin, perineural invasion and differentiated.

All diagnostic articles provide a short introduction to the normal anatomy and histology of the organ system involved followed sections explaining the standardised reporting elements. For example, the article 'invasive ductal carcinoma', includes sections describing tumour size and grade; multiple tumours; hormone receptor and human epidermal growth factor-2 (HER2) expression; and pathological stage. Simplified diagrams are included when appropriate to help illustrate both normal and abnormal features.

Cancer-related diagnoses and definitions were the most commonly read articles. Of these, articles describing cancers of the breast, colon and ovary were the most frequently accessed. However, articles explaining non-neoplastic conditions especially those in the endometrium, such as atrophic endometrium or disordered proliferative endometrium, have also been frequently accessed. In focus groups at TOH and UHN, patients using MyPathologyReport.ca felt more knowledgeable about their pathology results and better prepared to participate in their care.

Partnerships with patients, caregivers and their respective advocacy groups have been essential to the success of MyPathologyReport.ca. Working with TOH Publications Department, we have worked to develop clear language criteria for our authors to ensure a high level of readability for our articles. MyPathologyReport.ca has partnered with the Ottawa Regional Cancer Foundation and their team of Cancer Coaches to support health literacy for patients in the Ottawa region and across Canada. Cancer Coaches are healthcare professionals in oncology (Registered Nurses and Social Workers) that help patients navigate their cancer experience. We have been able to collaborate with their Cancer Coaches

who use the resources available on MyPathologyReport.ca to help patients read and understand their pathology reports.

An informed patient is an active member of the healthcare team. Our feedback demonstrates that both patients and clinicians find MyPathologyReport.ca to be a useful resource. We are continuing to add new content to the website on a monthly basis and encourage pathologists with an interest in patient education to contribute to the site. Our next steps involve longitudinal assessment of MyPathologyReport.ca from non-medical community members and evaluation of patient satisfaction and knowledge with access to this resource. We are also interested in collaborating directly with hospitals and other healthcare institutions to provide patients access to the resources on MyPathologyReport.ca directly from their EMR.

Take home messages

- ▶ Pathologists, are being called on to become more visible participants in patient care and to help foster an environment that empowers patients.
- ▶ Novel approaches have been undertaken by pathologists to improve patient communication and safety, including the addition of patient-friendly summaries at the beginning of pathology reports and the development of patient education tools.
- ▶ We developed MyPathologyReport.ca, a free online resource designed to help patients understand the language of pathology, to effectively navigate their pathology report and to illustrate the processes of obtaining a pathological diagnosis.

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Twitter Jason K Wasserman @DrJWasserman

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ORCID iD

Jason K Wasserman <http://orcid.org/0000-0003-3821-8956>

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